

Who Is Putting Whose Head In the Sand Or in the Clouds As the Case May Be?

As this tale unfolds it will be increasingly clear that my son is not only handicapped but disabled by anyone's criteria, including those of the Social Security Administration. Thus, my qualifications as a parent are unimpeachable. My qualifications as a professional in the field of mental retardation, however, are a matter of courtesy. Unlike Phil Roos, I was not a professional in the human services field before I was a parent; unlike Elsie Helsel, I did not go after another degree in special education; unlike Rud Turnbull, I did not have a profession I could turn directly toward the field to which my parenthood called attention. Only indirectly did my training in the discipline of science (my doctorate was in mathematical chemistry) help me in the early days to understand the limitations and constraints on the methods of the biological sciences and hence to serve for a while as an interpreter between those scientists and the parents who were eager for miracles from the laboratory.

In these days when certificates, diplomas, and guild membership cards are so often required as passports to participation in decision making, I am heartened to be able to report that I have only rarely been put down or excluded from human policy deliberations in which I judged myself competent. Moreover, I have been permitted to sit

and learn in many situations where I would not presume to speak, except to ask questions. To the ever-increasing body of professionals, especially those in universities and in government, who have permitted me to be productive in roles for which my credentials were distinctly unconventional, I owe, and warmly tender, sincere thanks. This is one respect in which my relationships with the professional community over the past quarter century have been exceptionally gratifying.

I am also fortunate in being old enough to have escaped the overbearing coercion of modern feminism which tends to judge productivity by the standards of the marketplace. I am proud to be the only person who has been continuously active in some volunteer capacity within the National Association for Retarded Citizens since I participated in its founding in 1950. I believe that NARC has a unique role to play, and that the existence of a strong collective lay advocacy group which continues to recognize and respond to the great diversity of need among persons called retarded is the single most essential element in securing their future. I have jealously guarded my amateur status within the association even when positions as a consultant and lecture fees have come my way on the outside. In the early days I carried out many unbudgeted assignments which are now executed by paid staff. In recent years I have been able to accentuate multiple linkages with other agencies and movements which no one with ties to a paid position could have made. The "cause" has taken me to forty-four states, plus Puerto Rico and ten foreign countries. It is hard to put a job title on the role I've played. One could say that I've been a social synergist with a predisposition toward communication and collaboration rather than confrontation.

That's the public or "professional" side. What of the private, the personal, the parental side? As we are all fond of telling each other, each person, each parent, each family experience is unique; yet there are common themes. How many of us, like Phil and Susan Roos, were told that we were overanxious, that our child's tardiness in meeting milestones was within normal limits? How many of us who founded local associations and organized the classes and recruited the executive directors now feel with Janet Bennett that local ARCs are no longer places where parents feel useful? How many of us like Tot Avis have seen the doctrines swing and now speculate about the potential orthodoxy of the eighties? Is still another perspective of any value? In an effort to give some integrity to this essay, I've selected some personal vignettes which I relate to three themes of concern to me: first, the discrepancy between the intents of public policy and the actualities of life for retarded individuals and their families; second, the mis-

match between research findings and both public policy and private practice (these themes are related, as it happens, to the work of the two NARC committees on which I have had the most extended service); third, the recurrent professional and societal denial of the differentness of the most disabled, and their resultant need for their own ergonomic (Note 1) environments.

This derogation of deviance may have as a secondary effect an unnecessary and inappropriate isolation of those people who, in fact, come face to face with this deviance as immediate care givers. It's not for nothing that a new magazine of growing circulation is called *The Exceptional Parent* or that George Tarjan (director of the Neuropsychiatric Institute, U.C.L.A.) considered it a major victory when the attendants at Pacific State Hospital were no longer reluctant to reveal where they worked.

Out of my personal experience, I've picked four vignettes to illustrate these themes. They deal with the *crisis*, *daily living*, *the right to education*, and the *institutionalization of deinstitutionalization*. I still live with the last theme as a current issue; my personal experience with the other three goes back a quarter of a century, but something tells me things haven't changed all that much.

The Crisis

Jonathan David Boggs was born on August 25, 1945. The date is significant for two reasons. It was the second Saturday after V-J Day and, as such, was the first Saturday on which my husband Fitzhugh Boggs had not put in a full day (eight to five) at the laboratory. Therefore, when I began having early labor pains about six o'clock on the morning of the twenty-fifth, it was not necessary for us to grapple with the decision as to whether or not he would go to work.

Some eight weeks before, I had resigned my own research job at the Explosives Research Laboratory at Bruceton, Pennsylvania. That was after V-E Day and after our group at the laboratory had completed its technical contributions to the design of the implosion device being put together at Los Alamos. At the Westinghouse Research Laboratories in East Pittsburgh, Fitzhugh had researched some of the radar jamming technology which had helped the Britons to win the Battle of Britain. At the time, neither of us knew what the other had contributed to the war effort.

We congratulated ourselves on our timing. It may have been more critical than we realized. With the end of the war, penicillin, which had previously been limited to use in military hospitals, was

released for civilian use. When David was ten days old, he became very ill. He had a high fever and a nervous twitching referred to as tetany. Several possible hypotheses were advanced as to the cause of the illness. Our pediatrician later told us that in all his considerable experience he had seen only one similar case. That child had died. An autopsy had shown an infection entering by way of the umbilical cord. David was treated with penicillin and survived. Many years later I was to address the Ways and Means Committee of the U.S. House of Representatives in support of extended authority for the Maternal and Child Health Program. My theme was "Survival Is Not Enough." Since then, a collaborative perinatal study supported by the National Institute of Health has yielded a technique for examining the discarded cord in the delivery room to detect such infections.

It was a harrowing three weeks. Dr. Gerald Caplan (1960) at Harvard has studied family crises of which ours was undoubtedly a classic example. As a crisis it was, I believe, well handled by the professionals. We were permitted to express our worries. No one denied the gravity of the situation. The physicians gave us their full attention and took care to explain the reasons for their several tentative diagnoses. They described the treatments, including a period of continuous lavage. A cousin of mine who is a registered nurse saw us through the transition from hospital to home which otherwise would have been still more frightening to me. David began to regain weight, and the doctors foretold no after effects.

But that was not the real crisis. The real crisis unfolded over the next twenty months. David first approached and then gradually—almost imperceptibly at first—fell behind the normal developmental timetable. When he was eight months old, our pediatrician asked us, apparently casually, whether we thought he could hear. We said we did not know. In fact, we were not sure until he was more than two years old when he responded to the sound of running bath water.

In the spring of 1946, David spent a month in the care of an aunt while Fitzhugh and I vacationed in Cuba where my parents were living at the time. Fitzhugh was between jobs, and it was the only opportunity we ever had for four consecutive weeks of vacation. If I had known then what I know now about critical periods of separation for infants, I would have arranged things differently. However, while we were away, David learned to roll over.

During the next ten months we were nomads. This was the immediate post-war era, and housing was at a premium. We had purchased a house in Upper Montclair, New Jersey, but were unable to evict the tenants (our legal effort to do so was put off by a technicality). As a result, David and I saw a succession of pediatricians. Each of them responded reassuringly to my description of his slow progress. When he was a little over a year and barely standing, the

pediatrician with whom I had hoped to settle down answered my query with "Well, he's prehensile, isn't he?"

In the face of being told repeatedly that David's progress was satisfactory, I did not share my own misgivings with Fitzhugh. As it turned out, he had his own. I seldom dream, or, to be more accurate, I do not recollect the dreams I have. Fitzhugh, by contrast, used to have consistent recurring dreams whenever he was confronted with a continuing problem. As he told me afterward, he had been having such dreams, always about David. They stopped immediately when we found a pediatrician who, without prompting from us, indicated that we had a problem.

It was only a partial resolution, however. Having delivered himself of the judgment that David might be self-supporting in a lowly occupation, he was not willing to assist us to obtain further medical consultation. I suppose he saw us as "shopping" parents. If so, it was a misjudgment on his part because we, in fact, were very grateful to him for admitting to the reality which we ourselves observed; namely, David was not developing at a normal rate. However, he resisted our request for a psychological evaluation and for further consultation on the medical side. Because of our appreciation, we felt considerable loyalty to him, and it was hard for us to break away. But eventually we did so, in order to obtain a comprehensive evaluation at Babies Hospital, the pediatric hospital associated with the College of Physicians and Surgeons in New York City. The doctors recommended institutionalization. By this time David was nearly three.

Following the findings of Dr. Caplan's (1960) studies of families in crisis, I see that this crisis, from our leading questions through an adequate analysis and reasonable exhaustion of remedies, was not well handled by the professionals involved. One would like to think that times have changed since then. Unfortunately, the word still has not gotten around. A young attorney friend of mine, well-acquainted with the field of mental retardation professionally, gave birth recently to a baby in a major Washington hospital. Tentative suspicion of Down's Syndrome on the basis of inspection was conveyed to her and her husband, but she had to fight to get a confirming cytogenetic study carried out. We also still hear reports of routine advice for instant institutionalization at birth.

Daily Living

We accepted the findings of the physicians' and surgeons' group as to the severity of David's impairment, along with its nonspecificity. We also accepted the notion that the underlying organic cause was not directly subject to remediation. (While putting himself through col-

lege, Fitzhugh had worked as a lab technician in a research department of neurology, and he had a rather vivid firsthand understanding of the effect of lesions in the central nervous system.) We did not, however, accept the group's advice to proceed with institutionalization. We were reinforced in this decision by David himself who gave us his response to the three or four days of hospitalization. As we got into the car, preparatory to leaving the hospital, he stood between us on the front seat and speechless as he was and is, gave us in body language the unmistakable message "Let's get the hell out of here!"

He lived with us until he was nearly seven. They were trying years in which we were largely on our own. Nevertheless, our efforts toward toilet training and self-feeding were to a considerable extent rewarded. But they were also years in which we could find no means to convey instructions or guidance to him about behavior which was either dangerous to him or productive of chaos in the household. His destructiveness did not convey a sense of rebellion or anger, but rather a total lack of comprehension that it was unacceptable to us. One had to be present physically to deter him from running into the street, destroying the neighbors' flowers, tearing up the magazines in the living room, removing the contents of the refrigerator, and getting up at night and pounding on the window just to hear the noise. Unfortunately, the neighbors also heard the noise and complained to the police.

I do not want to convey by this recitation that his motor development was normal. Indeed, by the time he was four, it was apparent that he had a mild cerebral palsy. Since then, this disability has become more apparent, and his contractions are now so severe that he walks a hundred feet with considerable difficulty.

The problem at that time, however, was one of accommodating extraordinary stress in the family's daily activities. Up until that time I had been a fairly meticulous housekeeper. However, the work of tidying and cleaning could be undone in thirty seconds by David's activities. In addition to caring for David, cleaning up after him would have been a full-time job, had I elected to do it. However, I saw the necessity for maintaining some time for my own intellectual pursuits as well as some outside activities, and we began to tolerate a high degree of disorder in the house. We removed most of the bric-a-brac and became resigned to the scarring of our furniture.

I had, by this time, postponed more or less indefinitely the notion of going back to professional work. I joined the League of Women Voters, a step that turned out to have been particularly useful since it taught me some important things about the operation of state government in New Jersey. I also began taking occasional courses at

what was then the Newark State Teachers College, now Kean College of New Jersey. The clinical psychologist who gave the course "Introduction to Tests and Measurements" told me about a clinic being organized by the brand-new Essex County Unit of the New Jersey Parents' Group for Retarded Children. This was truly a self-help group, and its dynamics were very different in those days than they are now that the professionals have largely taken over. But that is another story which I shall not tell here.

Rather, I wish to make some retrospective observations about this period from the point of view of support to parents and the prevention of parental burnout. Michael Bayley (1973), in reporting some sensitive British studies, documents the effects of the daily grind on families who retain a retarded member at home for many years. These deleterious effects can, in part, be mitigated. Christine Maslach (1976) has recently reported studies on burnout among various types of professional personnel who give direct care or service. These include social workers, child-care workers, attorneys, and others who constantly confront the insoluble problems of other people. Generally speaking, the confrontations of the professionals are limited to working hours. Even so, Maslach's research indicated that uninterrupted hours of direct contact, along with isolation from peers having similar duties, were factors in the vulnerability to such stress. She points out that when the stress becomes intolerable, the professional is likely to respond in one of two ways. He or she either cops out or begins to depersonalize the clients or patients and to blame them for their own misfortunes. Cop-out is possible, for example, when the social worker goes back to graduate school and takes a degree in administration. Both copping-out and depersonalization by staff work to reduce professional productivity and are detrimental to those being served. Maslach's findings suggest that limiting the duration of periods of exposure through planned direct contact and opportunities for peer group interactions can help to reduce burnout and thus enhance humanization for both care giver and care receiver. Although these studies did not include parents as subjects, it is fairly clear that there is a parallelism and hence a lesson to be learned and applied.

In retrospect, I can see that we in our situation had managed to apply some of these principles. We had what we referred to as a built-in baby-sitter. Having bought an old house with a third floor, we took advantage of a temporary post-war lifting of one-family zoning restrictions to create a small apartment there for a service man and his family. The apartment was rent-free to them as long as they were available on an intermittent and irregular but mutually agreeable schedule to look after David in our absence. This permitted us not

only to go out for an evening (which included participating in parent group meetings) but also to intersperse daytime routines with brief intermittent absences.

This model of respite care is, I believe, closer to the mark for both mother and child than is the all-day day-care center or the occasional fortnight of residential care which is more likely to be offered today. Quite frankly, I believe that we have not yet come to grips with reconciling what we know about the need of a child for a continuing and uniquely identified parent figure on the one hand, and the need to prevent burnout and to foster personhood in parents, especially mothers. I am speaking particularly of the first three or four years of the child's life. The National Collaborative Infant Project developed by the United Cerebral Palsy Association, with the cooperation of NARC and others, has demonstrated a model of early intervention which could displace group day-care for most very young handicapped children (Haynes, 1977). Quite aside from the services to the child, it combines assistance to mothers to enable them to be more effective parents, with brief spells of relief from the extraordinary demands of parenting a handicapped child. Both natural parents and foster parents need these supports. The significance of the high turnover already being noted among house parents in group homes should be studied against this hypothesis.

The Right to Education

The charter members of the Essex unit were a remarkably foresighted lot. By the time Fitzhugh and I came on board with them late in 1949, they had organized an interdisciplinary diagnostic clinic, to which a hardy band of professionals were contributing their time. The initial applicants were accepted by age groups so that the needs of a group could be identified for service planning. Soon there were enough six to nine year olds identified as trainable to justify organizing some classes. This was my first volunteer organizational task. Two classes were opened in October 1950, one in a Sunday school room, the other in a neighborhood house.

These children had been denied admission to local schools. However, we had a social mission in mind, so we, too, had some eligibility criteria. The children had to be toilet-trained and able to understand simple commands. Our mission was to persuade the county superintendent of schools, and through him the local superintendents, that such children could respond to skillful teaching in a classroom setting in a manner that invited accommodation in the public schools.

We were, in fact, going backward to the practices of the period from 1911 to 1930 when "imbecile" children had been accepted and provided with an approved curriculum in the larger communities in New Jersey. A state department of education publication of 1918 prescribes sense training, speech training, manual training, and "exercises of practical life." It then goes on to note "while results with this group are crude, the improvement in children is marked" (Anderson, 1918). It is hard to re-create now what these classes developed by the Essex unit meant to parents as well as children.

In connection with my duties, I enjoyed my first experiences of "professional" acceptance. I was permitted to sit in on the clinic team conferences at which recommendations were made relative to those children to be referred to me for class placement. I learned a lot from this, particularly as I was able to review the individual reports and watch the children they described over a period of time. It did not take me long to conclude that David would not be eligible for these classes.

About this time the neighboring local unit (Bergen-Passic) organized a summer day camp. Its admission standards were not as demanding as our classes. They claimed they could handle "anyone." The director urged me to send David, implying that my reluctance was an expression of overprotection. We agreed to give it a try, but some weeks later when I visited, I found David off in an enclave by himself, doing the same things as he did in the play yard at home.

But meanwhile I was also caught up in the group strategy to obtain legislation which would admit the children in our classes to public school, with a program suited to their needs. I became chairperson of the State ARC Education Committee. We studied the state constitution ["... a thorough and efficient system of public schools for the instruction of all the children in the state between the ages of 5 and eighteen years ..."] (Art. VIII, Sec. IV, Par. 1) and the law ["... courses of study suited to the age and attainments of all pupils ..."] (N.J.R.S. 18:11). Exclusions were permitted for contagious disease or behavior dangerous to others, but there was nothing about excluding pupils based on their IQ. Here again was that invisibility—that denial of the existence of exceptions. Suffice it to say that our strategy worked. In 1954 the governor signed a mandatory special education law (N. J. R. S. 18:46), replacing the one enacted in 1911 (the first in the nation), which had been rendered inoperative in effect by the school administrators. They had done so by labelling children with IQs below fifty as ineducable. Our use of the word "trainable" enabled us to accentuate the positive without getting into a confrontation on the issue of the three Rs. Our efforts were paralleled in other states.

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A national movement was under way. By 1952 I was chairperson of the NARC Education Committee. In 1954 NARC published a policy statement recommended by the committee, which I quote in full below:

AN EDUCATIONAL BILL OF RIGHTS FOR THE RETARDED CHILD

Every child, including every retarded child, is important and has the right to

1. Opportunities for the fullest realization of his potentialities, however limited, for physical, mental, emotional, and spiritual growth;
2. Affection and understanding from those responsible for his care and guidance during his years of dependence;
3. A program of education and training suited to his particular needs and carried forward in the environment most favorable for him, whether in the public schools, a residential center, or his own home;
4. Help, stimulation and guidance from skilled teachers, provided by his community and state as part of a broadly conceived program of free public education

And his parents have the right to determine for themselves, on the basis of competent advice, the course of care, training, and treatment, among those open to them, which they believe best for their family; and to have their decisions respected by others. (NARC, 1954)

When I was president of NARC (1958-60) and Gunnar Dybwad was executive, I suggested that we republish the preceding statement and give it a bit more play. When this did not happen, and I asked why, I was shown a letter from the current chairman of the Education Committee, who stated the opinion that the statement was unrealistic, that the schools would not accept the most severely and profoundly retarded, and that we were jeopardizing our chances for the trainable by making such sweeping demands. Perhaps she was right; despite the burgeoning literature about schooling for the profoundly retarded and zero reject, I still perceive some invisible children. In fact, when the director of a recent federally funded project asked for nominations of innovative programs for the very severely and profoundly retarded, he had to reject about half of them as not dealing with what the project had in mind. Even NARC once sponsored a film in which a typical child with Down's Syndrome was described as profoundly retarded. Anyway, Dr. Dybwad felt constrained to refrain from reissuing the 1954 policy.

The Institutionalization of Deinstitutionalization

Let me now skip, chronologically, to the present day. David is now thirty-two. He does not understand instructions, let alone any conversation which might enable him to anticipate what is going to happen. He has learned, however, to recognize a variety of situational clues. For example, certain observable activities precede mealtimes. The regularity of routine in daily living is therefore of considerably more significance to him than it would be were he able to receive oral or written alerts anticipating changes in that routine. He cooperates in the activities of daily living in which he is not entirely self-sufficient. It is thus important for him to be assisted by people who are well acquainted with his capabilities and his signals since he cannot tell them how to help him. Consistency by care givers and continuity of staffing are especially important for people whose disability includes the absence of communication skills. This is the best protection against "learned helplessness" (DeVellis, 1977).

David likes to eat, rock in a rocking chair, swing in a playground swing, ride in an automobile, and get into water, whether it be a shower or a swimming pool. There is a limit to the amount of time he or anyone else can spend in these activities, and, therefore, I must assume that he is bored or tuned out a good deal of the time, especially in the winter.

At the 1977 American Association on Mental Deficiency convention Dr. Burton Blatt gave an exquisite illustrated talk on the current documentation he and two colleagues have done on the state of affairs in institutions as contrasted with the state of affairs ten years ago (Blatt, 1977). There has been considerable progress, but his final message was that the people in institutions are lonely. One got the impression that loneliness is a function of the institution and that people in the community are not lonely. Subsequently, I made some observations in the hotel lobby. I was looking for a seat, and all the seats were occupied. With one or two exceptions, no one was talking to anyone else, and all of the people looked as solemn and as lonely as those in Dr. Blatt's film. There are a great many lonely people out in the community, and many of them are in foster care, group homes, boarding homes, nursing homes, and even in families. I would be lonely myself if I did not have the motivation, skill, energy, and independence to seek out contact and communication with other human beings. I think I would be particularly lonely if I were assigned to live with a small group of people not of my own choosing.

David's group is not small, however. Most of the members of the group of men with whom he lives are more capable in one or another respect than he. However, neither they nor he fit the nursing care model (those who need constant care from semi-skilled staff). Some

can talk a little; others can take advantage of the craft instruction which is offered. David does not participate, not only because he does not have the manual dexterity but because conceptually the product does not have meaning; and the process is not pleasing. The more capable men may leave the cottage alone and move about the grounds of the institution on their own recognizance; David must be escorted. On his own he would soon be on the highway or in the woods. One of the more capable men has selected David for paternalistic attention. Charlie sees to it that David gets his own chair back when it has been usurped by another. Charlie's advocacy is both expressive and instrumental. David benefits, but he does not really reciprocate. Indeed, there are very few people for whom David reserves his own enigmatic but gleeful smile. One of these is a young woman who was working as a cottage training technician while putting herself through college. It is a mark of the improvement of the way our institutions are run that she was permitted to express a little favoritism towards him.

She is now raising her own son. Recently she visited David while he was in the local hospital following some surgery. As the two of us watched him together, she mused, "I often wonder what he is thinking about, how the world looks to him." That thought is too infrequently pondered. If he were his own architect, how would David design his environment?

There are some parents who like the idea of normalization (Wolfensberger, 1972) because it is useful in glossing over the realities of difference. I sometimes think there are professionals who like it for the same reason. Rather than trying to create a "normal" environment for my son, I try to think of how the world must look from his point of view, and what kind of an environment would not only minimize his boredom and loneliness but enhance his sense of dominance. When I try to put myself in his skin, I realize that he, like me, has an immediate environment, a home; that is, the place where he sleeps, eats, and spends his leisure time with certain associates, and an immediate external environment which is called the community. His home environment could be improved from his point of view by reducing the noise level created by a really extraordinary architectural anomaly, reducing the size of and the number of people occupying the same daytime living space at the same time (i.e., subdividing the space appropriately), and reducing the total number of staff and residents with whom David has some interaction, provided this could be done in such a way as to retain in his "family" those people he would most like to have with him, while at the same time increasing autonomy and reducing the risk of burnout for the care-

givers. (The particular residential facility in which he now resides still maintains an overly hierarchical as distinct from a colleague pattern of organization of the direct care staff.) All this could be done equally well in any residential unit whether on campus or in the community.

But what of the community environment? The "community" surrounding David's "home" is the campus of the state school. It is an ergonomic community; that is, one which has been planned to suit the inhabitants. Its swimming pool is designed so that any one can stand up in any part of it. There is a twenty-mile hour speed limit on all its roads. Its doctors make house calls. Its respite care arrangements are always available, that is, when the parent surrogate has an emergency, another one is available. There is a restaurant where no one stares at the sloppy eaters. Nobody there thinks that it is inappropriate for a thirty-two-year-old man to use a swing on the playground by choice; it is not considered dehumanizing to let a man act like a child if he wants to. David is not restricted by any such environmental taboos.

From his point of view this community is more facilitative and more enhancing than the town half a mile down the road. There were times in the past when I deliberately escorted David into my community. Because he does not like to be in the water where he cannot put his foot firmly on the bottom of the pool, the area of the community swimming pool actually available to him was very small. On the public beach he would trample the neighboring family's picnic because he wanted their banana. The nurses in the general hospital put him into an enclosed crib (normal for children) which was too short for him. Being integrated into the community means nothing to him. Perhaps we should consider ways of making the community more aware that people with his extreme problems exist and need special care and attention. But first, I think we have to persuade the armchair policy-making professionals of their very existence.

How can we describe their extraordinary need for an adaptive environment structured to their requirements rather than ours? We need some new terminology, it seems. In a recent large meeting a well-known superintendent, who runs a facility in which there are residents like David, remarked that they had recently placed a number of profoundly retarded adults in the community, and that when these "profoundly" retarded adults were asked whether they would like to return to the institution, they all said, "No." I am sure that the adults to whom he referred were successfully placed, and I do not doubt their capacity and the voluntariness and lack of coercion in their expression of preference. If people who could make such a conceptual choice, who could understand the question, and express an answer

are called profoundly retarded, then we need some new term for those who cannot do any of these things.

Richard Willis (1973) did a time sample study in the late sixties of the interactions of the men residing in a residence hall for the severely and profoundly retarded. These men were able to move about; a large number of behaviors were coded. Unexpectedly, Willis observed that the men seemed to fall into two groups: those who exhibited a variety of behaviors scattered over all segments of the range; and those who failed to exhibit a large but discrete cluster of behaviors, many of which hinged around the area of communication. Willis observed that the absent behaviors appeared to be those which psychologists generally ascribe to homo sapiens but not to other primates. He called this group of residents noncultural. For this honest observation he received at least one derogatory review.

In discussing normalization, Wolfensberger (1972) has emphasized that many norms are culturally determined. Normal behaviors and normal settings are therefore not absolutely meritorious. Even the rhythms of life may vary from one society to another. Since cultures are created by and for the convenience and comfort of the members of a particular society, it would appear that subcultures are not only permissible but, for some purposes at least, ought to be encouraged. Successful societies are students of ergonomics; they fit the habitat to the inhabitants. If the inhabitants differ from one another, then so should the habitats and even the subcultures, ethnic or otherwise. In an era of divergent life styles, it seems particularly ironic that we place such stress on normalization for the retarded. Somehow the gap between public policy and private preferences seems great at times. Social reforms based on theoretical constructs are still pursued with the same missionary zeal as was the eugenics movement in times past.

I spend a great deal of time in Washington pondering the language of legislation and the rubrics of regulations. Most of the time I am working for the disabled, the retarded, the majority, but sometimes I try to relate what goes on there during the week with what I see when I bring David home on the weekend. Of all the things I have done to influence federal programs in the last twenty-two years, there are very few to whose impact I can trace any improvement in my son's well-being, although there have been improvements. There is one exception. In 1969 I helped to initiate the sequence of activities which led to the Intermediate Care Facilities/Mental Retardation (ICF/MR) legislation in 1971, and thus eventually to the controversial ICF/MR regulations of 1977 (Note 2). It seems likely that within the next two or three years the facility where my son resides may become an ICF/MR.

Ironically enough, I do not anticipate that this will bring about the improvements which I believe would be most conducive to significant recent research findings by a number of investigators working in various settings, on aspects of organizational structure and staff-resident interactions. (See, for example, Zigler and Balla, 1977; Raynes, 1977; Pratt et al., 1977; Moore et al., 1976; Wheeler, 1977.) The ICF/MR federal regulations deal with ratios of beds to rooms and staff to residents; although they may increase the direct care staff by a few additional positions, they will not change the way in which the staffing is organized or supervised. If the number of beds in David's bedroom is reduced from six to four, it will not make any difference to him. It will not change the layout of the day room or improve its acoustics (Gentry & Zimring, 1977). He will acquire an individual written habilitation plan. His case will be reviewed on paper somewhat more frequently, and this will raise the per capita cost, but little will change back at the cottage. Charlie will probably be classified as eligible for community placement in a group home, and he will leave. He will not have David to be concerned about. David will miss his defense against the more bossy residents, who will remain because their behavior will not be found acceptable in the group home.

Recently I was invited to give a talk at the NARC convention. I aired some of my concerns as a parent of a multiply handicapped, profoundly retarded adult son (Boggs, 1976). Nothing I have said or written in the past thirty years has occasioned such an outpouring of letters and comments by other parents. Some have adult children at home; others are parents of retarded persons who reside elsewhere. Several of these parents pointed out that they had spent many hours during the last ten or twenty years serving on local or state ARC boards, working for community services for children younger than their own, or working for legislation to aid the more numerous more able retarded, while the different needs of their own profoundly handicapped sons or daughters received less insightful study and attention. As Tot Avis has pointed out, it is difficult for parents who have accommodated themselves (perhaps reluctantly) to one professional doctrine to reverse directions when an apparently new doctrine supercedes. The parents who wrote to me, however, are not defenders of the status quo, nor are they sheep. Emotionally, they would like to see the son or daughter they know so well miraculously exhibit the capacity to move like his or her siblings into a life of "freedom and participation," to quote Burt Blatt (1977).

But what is "freedom"? What is "participation"? Is it freedom to be placed in a group home? Is it freedom to be allowed to make by default a vital decision that has consequences foreseeable by others but not by the maker? Is it participation to work for a wage you do not

earn on a job where your fellow workers are politely tolerant quickly exhaust any commonalities of interest in conversation? freedom to be forced to have and follow an individual habit plan?

These are questions to be addressed honestly by self-styled advocates for the retarded. But there is also the question of freedom of participation for their families. What parents are saying is "We are being ostracized, segregated, put down, for thinking unorthodox thoughts, for expressing the idea that an environment designed for normal people may not be the optimum for everyone."

In the early fifties, when NARC was very young, it still took courage for a parent to admit to having a retarded child, so great was the stigma. Although some professionals knew better, the public thought that the child reflected some bar sinister on the family cutcheon, a streak of degeneracy (Note 3). One of the great contributions made by Pearl Buck and Dale Evans Rogers, each of whom wrote books about their experiences as mothers of retarded children, was to enhance the self-image of parents; if these celebrities admitted without shame to having retarded children, then so could lesser folk. Although not in that league, my husband and I both recognized in the mid-fifties that we could fend off the blows fatal to other more vulnerable parents by using those Ph.D. degrees as shield and buckler. But it required some stamina, even so, to uphold a minority position to affirm that retarded children can be helped. Twenty-five years later it still does, even though the majority view we challenge may be different. Now the shield and buckler is not a rather irrelevant doctrine, but a personal examination of the right of one individual to be different, and of one parent to differ—and to be heard.

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Notes

1. According to the International Ergonomics Association, *ergonomics* is a word coined in 1950 from two Greek words, meaning the "natural laws of work." It is an interdisciplinary science dealing with the basic and applied aspects of human factors in work, machine control, and equipment design.

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2. The term *intermediate care facility* was introduced in 1967 when Congress sought to define a level of institutional care less than skilled nursing care but more than room and board. In 1971, Congress permitted public institutions for the retarded meeting certain specific standards to be eligible for medicaid reimbursement under this rubric.
3. In the early part of the century, the great leaders in the field of mental retardation—Fernald, Tredgold, Goddard—perceived feeble-mindedness as a discrete entity, but they also observed a more than chance coincidence in the same families with drunkenness and promiscuity. In the early fifties, it was customary to write off their observations as “methodologically unsound.” In the past five years we have discovered that there is indeed a fetal alcohol syndrome, some observers are also concerned that an increase in unmonitored teen-age pregnancies may once again make congenital syphilis a significant cause of mental retardation.